# Testimony of Kim Callinan, Chief Executive Officer, Compassion & Choices Regarding HB 5898, The Connecticut Aid in Dying for Terminally Ill Patients Act Joint Committee on Public Health March 18, 2019

#### Introduction

Good morning Chairman Steinberg, Chairwoman Abrams and Members of the Committee. My name is Kim Callinan, I am the CEO of Compassion & Choices, the nation's oldest and largest nonprofit organization working to improve care, expand options and empower everyone to chart their own end-of-life journey. I am grateful to be here with you today, to lift the voices of the more than 10,000 Connecticut supporters in every House and Senate district across the state. They include honoring the powerful stories of terminally ill Connecticut residents like Karina Danvers, who endures agonizing medical treatments to keep her HIV at bay, oncology nurse practitioner Sharon Hines, who suffers from brain cancer and stage IV lung cancer, and so many other Connecticut residents who want this option to die peacefully if their suffering becomes intolerable at life's inevitable end.

I urge you to make this the year we realize a more compassionate end of life for residents of Connecticut by passing HB 5989, The Connecticut Aid in Dying for Terminally Ill Patients Act. We strongly support the intent of the legislation. However, as explained below, we recommend several modifications to the bill based on more than 40 years of combined experience with authorized medical aid in dying across 8 jurisdictions. My testimony is broken up into several parts:

- The growing national and state movement
- The Evidence and Data from Oregon and Other Authorized States
- The Connecticut Legislation & How it Works
- Recommended Improvements to the Connecticut Legislation

http://newoldage.blogs.nytimes.com/2011/08/24/deciding-to-die-then-shown-the door/? ref=health; Uyttebrouck, "Couple Transported Out of Facility After Refusing Food," *Albuquerque Journal*, Jan. 08, 2011, available at <a href="http://www.abgjournal.com/news/metro/08232859metro01-08-11.htm">http://www.abgjournal.com/news/metro/08232859metro01-08-11.htm</a>.

<sup>&</sup>lt;sup>1</sup> Compassion & Choices brought landmark federal cases establishing that dying patients have the right to aggressive pain management, including palliative sedation. *Vacco v. Quill, 521 U.S. 793 (1997); Washington v. Glucksberg*, 521 U.S. 702 (1997).

<sup>&</sup>lt;sup>2</sup> Compassion & Choices drafted and sponsored introduction of legislation requiring comprehensive counseling regarding end-of-life care options. See, California Right to Know End-of-Life Options Act, Cal. Health & Safety Code §442.5; New York Palliative Care Information Act, N.Y. Pub. Health Law § 2997-c.

<sup>&</sup>lt;sup>3</sup> For example, Compassion & Choices is pursuing accountability for failure to honor a patient's wishes as documented in a POLST, *DeArmond v Kaiser*, No. 30-2011-00520263 (Superior Court, Orange County, CA). In another case, Compassion & Choices represented a family in bringing into the public eye a situation where patient wishes to forego food and fluid were obstructed. See Span, "Deciding to Die, Then Shown the Door," *The New York Times*, Aug. 24, 2011, available at

<sup>&</sup>lt;sup>4</sup> Compassion & Choices brought two federal cases to the United States Supreme Court urging recognition of a federal constitutional right to choose aid in dying. *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill, 521 U.S. 793(1997)*. Compassion & Choices was in leadership in the campaigns to enact the Death with Dignity Acts in Oregon and Washington. Or. Rev. Stat. § 127.800 (2007); Wash. Rev. Code Ann. § 70.245 (West 2011).

<sup>&</sup>lt;sup>5</sup> See supra n. 1, Bergman, Tomlinson, Tolliver, Hargett; See supra n. 3, DeArmond.

Common Misconceptions about Medical Aid in Dying

# What is Medical Aid in Dying?

Medical aid in dying is a medical practice in which a mentally capable, terminally ill adult with six months or less to live has the option to request a doctor's prescription for medication that they can decide to take to die gently in their sleep if their suffering becomes unbearable.

# **The Growing Movement**

Since this bill was before you last session, the public demand for this end-of-life care option has continued to grow. As a result, the medical community and lawmakers are recognizing the value and importance of this legislation by dropping their prior opposition to it, or adopting supportive policies and passing laws to authorize the practice. In 2017 and 2018 alone, 127 state legislators served as primary sponsors of medical aid-in-dying bills introduced in 28 states. Four new jurisdictions have authorized medical aid in dying in just the last three years. In contrast, it took 19 years for the first four states to authorize this option. The movement's momentum is self-evident.

Today, nearly one in five people...19 percent...live in a jurisdiction where medical aid in dying is authorized either through statute or court decision. This list includes seven states: Oregon (1994, ballot initiative),<sup>6</sup> Washington (2008, ballot initiative),<sup>7</sup> Montana (2009, state Supreme Court decision),<sup>8</sup> Vermont (2013, legislation),<sup>9</sup> California (2015, legislation),<sup>10</sup> Colorado (2016, ballot initiative)<sup>11</sup> and Hawaii (2018, legislation),<sup>12</sup> as well as the District of Columbia (2016, legislation)<sup>13</sup>

http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ors.aspx.

<sup>&</sup>lt;sup>6</sup> Oregon Death With Dignity Act. Oregon Revised Statute. Chapter 127. Enacted October 27, 1997. Available from

<sup>&</sup>lt;sup>7</sup> Washington Death With Dignity Act. Complete Chapter 70.245 RCW, Complete Chapter. Enacted November 4, 2008. Available from http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245.

<sup>&</sup>lt;sup>8</sup> Montana Supreme Court Ruling Baxter v. Montana. December 2009 Available from <a href="https://www.compassionandchoices.org/wp-content/uploads/2017/01/Montana-Supreme-Court-Opinion.p">https://www.compassionandchoices.org/wp-content/uploads/2017/01/Montana-Supreme-Court-Opinion.p</a>

<sup>&</sup>lt;sup>9</sup> Vermont Patient Choice and Control at the End of Life Act. Act 039, Chapter 113. Enacted May 2013. Available from http://www.leg.state.vt.us/docs/2014/Acts/ACT039.pdf

California End of Life Option Act. SB-128 End of Life. Enacted October 2015. Available from http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=201520160SB128&search\_keywords=
 Colorado End of Life Options Act, Proposition 106, Passed November 8, 2016, Pending implementation. Retrieved from:

http://coendoflifeoptions.org./wp-content/uploads/2016/06/Full-Text-of-Measure.pdf

<sup>&</sup>lt;sup>12</sup> Hawaii Our Care, Our Choice Act, HB 2739, Signed April 4, 2018. Pending Enactment. Available from: https://www.capitol.hawaii.gov/session2018/bills/HB2739 HD1 .pdf

<sup>&</sup>lt;sup>13</sup> District of Columbia, Death with Dignity Act, Available from: <a href="https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page\_content/attachments/Death%20With%20Dignity%20Act.FINAL\_.pdf">https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page\_content/attachments/Death%20With%20Dignity%20Act.FINAL\_.pdf</a>

Public polls<sup>14,15,16,17</sup> consistently demonstrate that by more than a 2-1 margin (63% vs. 31%), Connecticut registered voters support medical aid in dying, and passage of this legislation. Support for the bill is bipartisan and diverse, spanning every demographic group measured.

These results are consistent with national polling. Medical aid in dying receives support from the vast majority of voters...and majority support among nearly every demographic group...as measured by national independent polling outlets. A 2015 Gallup poll<sup>18</sup> also noted that support had "risen nearly 20 points in the last two years" and stands at the highest level in more than a decade." Support since that time has continued to climb, with 72 percent of voters supporting medical aid in dying in the most recent May 2018 Gallup survey.<sup>19</sup>

In 2016, LifeWay Research, a historically conservative, religious organization, released a survey, which concluded national support for medical aid in dying at 67 percent. The survey also demonstrated that majority support spanned a variety of demographic groups, including white Americans (71%), Hispanic Americans (69%), more than half of Black, Non-Hispanic Americans (53%); adults aged 18 to 24 (77%), 35 to 44 (63%) and 55 to 64 (64%); with some college education (71%), with graduate degrees (73%) and with high school diplomas or less (61%). Majority support also included most religious denominations, including Christians (59%), Catholics (70%), Protestants (53%), those of other religions (70%) and those who identified as non-religious (84%).

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<sup>&</sup>lt;sup>14</sup> Low Dem Support Hurts Connecticut Gov. Malloy, Quinnipiac University Poll Finds; Voters Say No To More Casinos 4-1. Quinnipiac University. March 2015. Available from: <a href="http://www.quinnipiac.edu/news-and-events/quinnipiac-university-poll/connecticut/release-detail?ReleaselD=2174">http://www.quinnipiac.edu/news-and-events/quinnipiac-university-poll/connecticut/release-detail?ReleaselD=2174</a>.

<sup>&</sup>lt;sup>15</sup> Connecticut Voters Back Suicide Bill Almost 2-1, Quinnipiac University Poll Finds: Voters Call Gov. Malloy's Tax Refund a Gimmick. Quinnipiac University. March 2014. Available from: http://www.quinnipiac.edu/images/polling/ct/ct03062014 g95hjs.pdf.

<sup>&</sup>lt;sup>16</sup> Voters + Disabled Community. Connecticut Survey. Purple Insights. February 2014. Available from: <a href="https://drive.google.com/a/compassionandchoices.org/file/d/0B3luDjCAxxv7bF9ETDgzS1B2RmJ1aWdM">https://drive.google.com/a/compassionandchoices.org/file/d/0B3luDjCAxxv7bF9ETDgzS1B2RmJ1aWdM</a> UGRqeHJibVdIUWI0/view?usp=sharing.

<sup>&</sup>lt;sup>17</sup> Aid in Dying Polling Results. Momentum Analysis-Connecticut. May 2012. Available from: https://drive.google.com/en?id=0B3luDjCAxxv7d3R3TWM1NmQ4WHZLN2htOXVCOTJzZzY4OFY4

<sup>&</sup>lt;sup>18</sup> Dugan, A. In U.S., Support Up for Doctor-Assisted Suicide. Gallup. May 2015. Available from <a href="http://www.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx?utm\_source=Politics&utm\_medium=newsfeed&utm\_campaign=tiles">http://www.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx?utm\_source=Politics&utm\_medium=newsfeed&utm\_campaign=tiles</a>.

<sup>&</sup>lt;sup>19</sup> Brenan, Megan, Americans' Strong Support for Euthanasia Persists, May 31, 2018. Available from: https://news.gallup.com/poll/235145/americans-strong-support-euthanasia-persists.aspx?g\_source=link\_ NEWSV9&g\_medium=NEWSFEED&g\_campaign=item\_&g\_content=Americans%27%2520Strong%2520 Support%2520for%2520Euthanasia%2520Persists

<sup>&</sup>lt;sup>20</sup> American Views on Assisted Suicide, LifeWay Research, September, 2016. Available from: http://lifewayresearch.com/wp-content/uploads/2016/12/Sept-2016-American-Views-Assisted-Suicide.pdf

Among U.S. physicians, support for medical aid in dying is also strong. A December 2018 Medscape survey<sup>21</sup> of 5,200 U.S. physicians from 29 specialties demonstrated a significant increase in support for medical aid in dying from 2010. Today well over half (58%) of the physicians surveyed believe that: "...physician assisted death should be made legal for terminally ill patients."

Most of the medical associations in authorized states currently have neutral positions on medical aid in dying including Oregon,<sup>22</sup> California,<sup>23</sup> Colorado,<sup>24</sup> Vermont,<sup>25</sup> Hawaii<sup>26</sup> and the District of Columbia.<sup>27</sup> Just this past February, the Connecticut Medical Society dropped its longstanding opposition and adopted a position of engaged neutralits.<sup>28</sup>

And numerous national professional medical and health organizations have endorsed or dropped their opposition to medical aid in dying in response to growing support for this palliative care option among physicians and the public.<sup>29</sup> The American Academy of Family

<sup>&</sup>lt;sup>21</sup> Martin, Keith L., Medscape Ethics Report 2016: Life, Death, and Pain, December 12, 2018 Available from: <a href="https://www.medscape.com/slideshow/2018-ethics-report-life-death-6011014#1">https://www.medscape.com/slideshow/2018-ethics-report-life-death-6011014#1</a>

<sup>&</sup>lt;sup>22</sup> Oregon Medical Association. Excerpted from: WWS Section on Hospice-End of life Care-Death & Dying. Date unknown. Available from

https://drive.google.com/file/d/0B3IuDjCAxxv7clQwYzdlWjZEb0xqbFE4eWRHbTMzNVhsck00/view?usp=sharing

<sup>&</sup>lt;sup>23</sup> California Medical Association. Excerpted from: CMA changes stance on physician aid in dying, takes neutral position on End of Life Option Act. June 2, 2015. Available at

http://www.cmanet.org/news/detail/?article=cma-changes-stance-on-physician-aid-in-dying.

24 Colorado Medical Society, Statement by CMS President-elect Katie Lozano, MD, FACR, regarding

Ballot Proposition 106. Available from:

http://www.cms.org/articles/statement-by-cms-president-elect-katie-lozano-md-facr-regarding-ballot-prop

<sup>&</sup>lt;sup>25</sup> Vermont Medical Society, Resolution, Policy on End-of-life-Care, Adopted November 4, 2017. Available from: <a href="http://www.vtmd.org/sites/default/files/2017End-of-Life-Care.pdf">http://www.vtmd.org/sites/default/files/2017End-of-Life-Care.pdf</a>

<sup>&</sup>lt;sup>26</sup> Hawaii Lawmakers to Hear Controversial Death with Dlgnity Bill, Hawaii News Now, February 15, 2017. Available from:

http://www.hawaiinewsnow.com/story/34510162/hawaii-lawmakers-to-hear-controversial-death-with-dignit y-bill

<sup>&</sup>lt;sup>27</sup> The Medical Society of the District of Columbia takes a neutral position on medical aid in dying, Available from:

http://www.msdc.org/?page=MSDCAdvocacy&hhSearchTerms=%22death+and+dignity%22

<sup>&</sup>lt;sup>28</sup> Connecticut Medical Society, Position Statement on Medical Aid-in-Dying, February 2019. Available from:

https://gallery.mailchimp.com/9342ca2167afd1d7acac84254/files/5cc2f8e9-f396-4f47-ad49-a61fe555cf2a/ Aid in Dying Policy Final.pdf

<sup>&</sup>lt;sup>29</sup> Healthcare Professional Organizations that Recognize Medical Aid in Dying, Compassion & Choices Fact Sheet, Available from: <a href="https://drive.google.com/file/d/0B3luDjCAxxv7UTdKemdGbW81Zms/view">https://drive.google.com/file/d/0B3luDjCAxxv7UTdKemdGbW81Zms/view</a>

Physicians;<sup>30</sup> American Public Health Association,<sup>31</sup> and the American Academy of Hospice and Palliative Medicine<sup>32</sup> all now have neutral or supportive positions.

# A Solid Body of Evidence: The Experience in Oregon and Other Authorized Jurisdictions

This growing support for medical aid in dying is in part because it is a time-tested end-of-life care option and it protects patients. Over the years, opponents of medical aid-in-dying legislation have promoted and publicized many hypothetical scenarios and unsubstantiated anecdotal claims. *Their dire predictions have simply not been borne out.* The evidence is clear: the Connecticut legislation, which is modeled after other authorized jurisdictions, will protect patients, support the doctors who treat them and provide patients with a compassionate option for dying peacefully. I offer the following facts:

## Medical Aid in Dying Protects Patients

There have been no documented or substantiated incidents of abuse or coercion across 8 jurisdictions for a combined 40 years: California, Colorado, Hawai'i, Montana, Oregon, Vermont, and Washington, as well as the District of Columbia.

Relatively Few People will Use Medical Aid in Dying, But Many Benefit from These Laws While less than 1% of people who die annually in Connecticut will decide to use the law, based on data from other jurisdictions, large numbers will benefit from simply knowing the law exists. Awareness that the law is there has a palliative effect, relieving worry and providing comfort. Furthermore, a third or more of those who receive an aid-in-dying prescription never even take the medication. However, they report having enormous peace of mind from the moment they obtained the prescription because their fears of suffering were alleviated. Quite simply, medical aid in dying is a prescription for comfort and peace of mind.

Aid-in-dying medication, like other potent medications for pain and agitation, are safely stored and discarded, according to state<sup>34</sup> and federal guidelines.<sup>35</sup>

American Academy of Family Physicians COD Addresses Medical Aid in Dying, Institutional Racism.
 October 10, 2018. Available from: <a href="https://www.aafp.org/news/2018-congress-fmx/20181010cod-hops.html">https://www.aafp.org/news/2018-congress-fmx/20181010cod-hops.html</a>
 American Public Health Association, Excerpted from: Patient's Rights to Self-Determination at the End.
 Policy # 20086. October 28, 2008. Available from

 $<sup>\</sup>underline{https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}$ 

<sup>&</sup>lt;sup>32</sup> American Academy of Hospice & Palliative Medicine. Excerpted from: Statement on Physician-Assisted Death, February 14, 2007. Available from <a href="http://aahpm.org/positions/pad">http://aahpm.org/positions/pad</a>
<sup>33</sup> Kathy L. Cerminara & Alina Perez, *Empirical Research Relevant to the Law: Existing Findings and Future Directions*, *Therapeutic Death: A Look at Oregon's Law*, 6 Psychol. Pub. Pol'y & L. 503, 512–13 (2000).

<sup>&</sup>lt;sup>34</sup>Connecticut Chapter 420b\*, Dependency-Producing Drugs. Sec. 21a-252. (Formerly Sec. 19-460). Prescription and dispensing of controlled substances by certain practitioners. Surrender of unused substances by patients. Available from: <a href="https://www.cga.ct.gov/2017/pub/chap\_420b.htm">https://www.cga.ct.gov/2017/pub/chap\_420b.htm</a>
<sup>35</sup> U.S. Food and Drug Administration, Ensuring Safe Use of Medicine, Safe Disposal of Medicine. Available from:

# For Some Terminally III People, Comfort Care and Pain Management Is Not Enough to Relieve Suffering

While pain is less frequently noted in the Oregon report as a reason terminally ill adults request the option of medical aid in dying, it is important to note that the attending physician, not the terminally ill individual, completes the form. Studies suggest that doctors often underestimate pain levels.<sup>36</sup>

The evidence from scientific studies confirms that despite the wide availability of hospice, palliative care and pain management, up to 51% of patients<sup>37</sup> experience pain at the end of life. The prevalence of pain has been noted to increase significantly in the last 4 months of life and reaching as high as 60% in the last month of life.<sup>38</sup> Additionally, breakthrough pain (severe pain that erupts even when patient is already medicated with a long-acting painkiller) remains a nightmare experience for many patients. It has been estimated that between 65% and 85% of patients with cancer -- by far the most common disease among people who request medical aid in dying -- experience significant pain.<sup>39</sup>

# People Decide to Use Medical Aid in Dying to Relieve Suffering

What we hear directly from the terminally ill individuals is that people choose to use the law for multiple reasons all at once: pain and other symptoms, like breathlessness and nausea, loss of autonomy, loss of dignity. It is not any one reason, but rather it is the totality of what happens to one's body at the very end of life. For some people, the side effects of treatments, such as chemotherapy or pain medication (sedation, relentless nausea, crushing fatigue, obstructed bowels, etc.) are just as bad as the agonizing symptoms of the disease. For others, they want the option of medical aid in dying because they want to try that one last long-shot treatment with the peace of mind of knowing that if it results in unbearable suffering, they have an option to peacefully end it.

This experience is consistent with 21 years of data in Oregon, where doctors are asked to select the top reasons people decide to use the law. The collective reasons total nearly 400%. Doctors recognize that people decide to use medical aid in dying for multiple

https://www.fda.gov/drugs/resourcesforyou/consumers/buyingusingmedicinesafely/ensuringsafeuseofmedicine/safedisposalofmedicines/ucm186187.htm

<sup>&</sup>lt;sup>36</sup> Anderson KO, Mendoza TR, Valero V, Richman SP, Russell C, Hurley J, DeLeon C, Washington P, Palos G, Payne R, Cleeland CS. Minority cancer patients and their providers: pain management attitudes and practice. Cancer. 2000;88:1929–1938.

<sup>&</sup>lt;sup>37</sup> Sykes, N., & Thorns, A. (2003). The use of opioids and sedatives at the end of life. The Lancet Oncology, 4(5), 312–318. Available from:

http://www.ldysinger.stjohnsem.edu/ThM\_590\_Intro-Bioeth/15\_palliative\_care/2003%20Lancet%20-%20The%20use%20of%20opioids%20and%20sedatives%20at%20the%20end%20of%20life.pdf

<sup>&</sup>lt;sup>38</sup> Smith, A. K., Cenzer, I. S., Knight, S. J., Puntillo, K. A., Widera, E., Williams, B. A., Boscardin, W. J., & Covinsky, K. E. (2010). The epidemiology of pain during the last 2 years of life. Annals of Internal Medicine, 153(9), 563–569. Available from:

http://annals.org/aim/article/746344/epidemiology-pain-during-last-2-vears-life

<sup>&</sup>lt;sup>39</sup> Jeri Ashley, RN, MSN, AOCNS, CCRS; James T. D'Olimpio, MD, FACP; Breakthrough Pain in Patients with Cancer: Essential Concepts for Nursing, Pharmacy, Oncology, and Pain Management Medscape, 11/19/2009. Available from: <a href="http://www.medscape.org/viewarticle/712261">http://www.medscape.org/viewarticle/712261</a>

reasons and it is the totality of suffering at the end of life that motivates them to use this option.

Only the dying person can determine how much pain and suffering is too much. This law puts the decision in the hands of the dying person, in consultation with their doctor and loved ones, rather than forcing them to abide by a blanket government rule.

# Requests for Medical Aid in Dying Are Not a Failure of Hospice or Palliative Care

Terminally ill people who request medical aid in dying do not make them because hospice or palliative care has failed to provide the best symptom control available. Some agonies simply cannot be controlled or relieved, unless a person is willing to be sedated to complete and deep unconsciousness. And good hospice services and palliative care do not eliminate the need of medical aid in dying as an end-of-life care option. Terminally ill people should have a full range of end-of-life care options, whether for disease-specific treatment, palliative care, refusal of life-sustaining treatment and the right to request medication the patient can decide to take to shorten a prolonged and difficult dying process. Only the dying person can decide whether their pain and suffering is too great to withstand. The option of medical aid in dying puts the decision-making power where it belongs: with the dying person.

# Medical Aid in Dying Improves End-of-Life Care

The data also demonstrates that medical aid in dying results in one very exciting, unintended positive outcome: it improves other aspects of end-of-life care! Data demonstrate the implementation of medical aid in dying contributes to more candid conversations between doctors and patients; higher hospice usage rates and improved palliative care training for physicians. A survey of doctors about their efforts to improve end-of-life care since medical aid in dying became available showed 30 percent of responding physicians had increased referrals to hospice care, and 76 percent made efforts to improve their knowledge of pain management. Furthermore, a 2015 Journal of Palliative Medicine study on hospice usage patterns suggested the law may have contributed to more open conversations between doctors and patients about end-of-life care options, higher hospice usage rates, lower rates of hospice misuse.

# HB 5898, The Connecticut Aid in Dying for Terminally Ill Patients Act

The bill you are considering is modeled after the 1994 Oregon Death with Dignity Act, which was drafted more than 20 years ago, during a time when no other state authorized the medical practice of medical aid in dying. In a growing number of jurisdictions, lawmakers like yourselves are examining the Oregon experience over the last 21 years (1998-2018)<sup>42</sup> and developing legislative approaches that are appropriate for them. HB

<sup>&</sup>lt;sup>40</sup>Ganzini L, Nelson HD, Lee MA, Kraemer DF, Schmidt TA, Delorit MA. Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act. JAMA. 2001;285(18):2363-2369. doi:10.1001/jama.285.18.2363

<sup>&</sup>lt;sup>41</sup> Wang SY, Aldridge MD, Gross CP, et al. Geographic Variation of Hospice Use Patterns at the End of Life. J Palliat Med. 2015;18(9):771-80.

<sup>&</sup>lt;sup>42</sup> Oregon Public Health Division, <u>Oregon's Death with Dignity Act, 2018 Summary</u>

5898 is sound legislation for a compassionate medical practice based on a proven track record.

# Established Process: Eligibility Criteria and Core Safeguards

HB 5898 establishes strict eligibility criteria and guidelines to ensure the highest standard of care for the medical practice of aid in dying, as described in clinical criteria published in the prestigious, peer reviewed Journal of Palliative Medicine. To be eligible for aid-in-dying medication, an adult resident of the state must be terminally ill, with a prognosis of six months or less to live, mentally capable of making their own healthcare decisions and physically capable of ingesting the medication. In addition to the strict eligibility criteria, HB 5898 establishes core safeguards, including that the attending physician must inform terminally ill adults requesting medical aid in dying about other end-of-life care options, including comfort care, hospice care, pain control and palliative care.

# Additional Regulatory Requirements

HB 5898 requires that a consulting physician must confirm the attending physician's terminal diagnosis, prognosis of six months or less to live and mental capability of the terminally ill individual requesting this option and the person's physical capability to self-ingest the aid-in-dying medication. If either the attending or consulting physician is unable to determine whether the individual has mental capacity to make an informed health care decision, a mental health professional (psychiatrist or psychologist) must evaluate the individual and ensure that they are capable of making their own healthcare decisions prior to a prescription being written.

The terminally ill adult must make two verbal requests to their doctor; the doctor must offer the individual multiple opportunities to withdraw their request; and inform the individual that they may withdraw their request at any time or decide not to take the medication.

# **Voluntary Participation**

A healthcare provider is free to decide whether or not to participate in medical aid in dying under this legislation. In fact, the bill specifically says that no doctor or pharmacist is obligated to prescribe or dispense aid-in-dying medication. However, if a doctor is unable or unwilling to honor a patient's request and the patient transfers their care to a new provider, the prior provider must transfer a copy of the patient's relevant medical records to the new physician. The legislation protects physicians who do decide to participate from criminal and civil liability, and professional discipline, as long as they comply with the law and act within the standards of medical care.

# **Physician Participation**

https://www.compassionandchoices.org/wp-content/uploads/2016/04/Clinical-Criteria-for-Aid-in-Dying.pdf

<sup>&</sup>lt;sup>43</sup> Orentlicher, D., Pope, T.M., Rich, B.A. (2015) Clinical Criteria for Physician Aid in Dying. Journal of Palliative Medicine. 18(x): 1-4. Available from:

A growing number of physicians would like the option to support their patients" requests for medical aid in dying. According to a 2017 Medscape survey, 57 percent of those who practice in states that do not explicitly authorize medical aid in dying said they had been in a situation in which they wished the patient could have been able to exercise that option. The data from authorized states demonstrates that hundreds of doctors are supporting the relatively small number of patients who want this option.

- The 2018 Oregon Report<sup>45</sup> indicates that a total of 103 physicians wrote 249 qualified terminally ill individuals aid-in-dying medication.
- The 2017 Washington Report<sup>46</sup> notes 115 different physicians prescribed 212 qualified terminally ill individuals aid-in-dying medication.
- The 2017 California Report<sup>47</sup> identified 241 unique physicians prescribed 577 qualified terminally ill individuals aid-in-dying medication.
- The 2018 Colorado Report<sup>48</sup> indicates 66 physicians prescribed 125 qualified terminally ill individuals aid-in-dying medication.

#### Criminal Conduct

Additionally, HB 5898 establishes that any person who, without authorization from the patient, willfully alters, forges, conceals or destroys an instrument, a reinstatement, or revocation of an instrument or any other evidence or document reflecting the terminally ill individual's desires and interests with the intent and effect of hastening the death of the individual, is guilty of murder.

# **Recommendation to improve the Connecticut Legislation**

Compassion & Choices recommends amending HB5898 to make the changes cited below. The proposed changes also are included in a marked up bill, which is attached to my testimony:

# Remove provisions that will result in unnecessary government red tape

Compassion & Choices is pleased to see that HB 5898 contains the same strict eligibility criteria and core safeguards legislated in the jurisdictions that currently authorize medical aid in dying. We believe these core safeguards are the primary reason the <u>Journal of</u>

<sup>&</sup>lt;sup>44</sup> News > Medscape Reader Polls, Physician-Assisted Death: Where Do You Stand? January 12, 2017 Available from: <a href="https://www.medscape.com/viewarticle/874341">https://www.medscape.com/viewarticle/874341</a>

<sup>&</sup>lt;sup>45</sup> Oregon Public Health Division, <u>Oregon's Death with Dignity Act</u>, <u>2018 Summary</u>

<sup>&</sup>lt;sup>46</sup> Washington Death with Dignity Annual Report, 2017 Available from: <a href="https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2017.pdf">https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2017.pdf</a>

<sup>&</sup>lt;sup>47</sup> California Department of Public Health, 2017 End of Life Option Act Data Summary. Available from: <a href="https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADataReport.pdf">https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADataReport.pdf</a>

<sup>&</sup>lt;sup>48</sup> Colorado Department of Public Health and Environment, Colorado End of Life Option Act 2018 Data Summary. Available from:

https://drive.google.com/file/d/1FmoyCcL2gHopDO9rCJ2lGFEMUye8FQei/view

<u>Medical Ethics</u> concluded in 2008 that: "Rates of assisted dying (in Oregon)...showed no evidence of heightened risk for the elderly, women, the uninsured...people with low educational status, the poor, the physically disabled or chronically ill...people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations."<sup>49</sup>

While we understand your goal to protect patients, as drafted this legislation includes regulatory roadblocks that will severely limit, if not eliminate, the ability of terminally ill patients to use medical aid in dying to peacefully end their suffering. A large and robust body of data demonstrates that medical aid in dying has been effectively practiced in authorized jurisdictions -- without these additional requirements -- for a combined 40 years without a single case of abuse, coercion or misuse. The data also demonstrate that the current process for qualifying medical aid in dying is already unnecessarily cumbersome and prevents eligible people from accessing these laws. For example, a study by Kaiser Permanente Southern California published in Journal of the American Medical Society [JAMA] Internal Medicine showed that about one-third of eligible patients who requested the option of medical aid in dying were not able to complete the process and obtain a prescription before they died.<sup>50</sup> This Kaiser study was conducted in a supportive health system. Imagine the experience of a dying person trapped in a system that refuses to allow doctors to participate in medical aid in dying. These patients are forced to find a new health system and re-establish care with a new doctor before they can even begin the process! Finding a new doctor you can trust to honor your wishes is a challenge for most of us; imagine trying to accomplish this feat if you are dying.

The robust body of evidence demonstrates that the Oregon law model includes more than enough regulations to protect patients. The addition of more regulations will only serve as roadblocks to dying patients. We are specifically concerned with three provisions that could limit access to the very people the bill is intended to serve.

• The proposed bill requires one oral request and two written requests. Under existing medical aid-in-dying laws, a terminally ill individual is required to make two oral requests and submit one written request. These requirements are already ensure patient safety -- additional requirements are not necessary -- and only put more barriers in front of dying patients with limited energy and time to get over them.

<sup>&</sup>lt;sup>49</sup> Battin MP, van der Heide A, Ganzini L, et al Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups Journal of Medical Ethics 2007:33:591-597.

<sup>&</sup>lt;sup>50</sup> Nguyen HQ, Gelman EJ, Bush TA, Lee JS, Kanter MH. Characterizing Kaiser Permanente Southern California's Experience With the California End of Life Option Act in the First Year of Implementation. *JAMA Intern Med*.2018;178(3):417–421. doi:10.1001/jamainternmed.2017.7728

- The bill requires each of the two required written requests to be witnessed by two different people, totaling four (4) witnesses. None of these four witnesses may be a family member or person in a position to inherit any portion of the terminally ill individual's estate upon death: Under existing medical aid-in-dying laws, two witnesses who personally know the dying person have to attest that the person is making a voluntary, informed decision, without undue influence or coercion. One of the two required witnesses must not be a family member or person in a position to inherit any portion of the terminally ill individual's estates upon death. The addition of two more witnesses is extremely burdensome and discriminates against people who have progressed so far in their disease or are so old that they have few remaining social contacts outside their families.
- The bill unnecessarily restricts the working relationship of attending physicians and consulting physicians by mandating that they "may not routinely share office space." Given the challenges presented by a scarce number of medical providers and rampant healthcare organization mergers, unnecessarily restricting the working relationships of physicians stands will limit access to medical aid in dying. It also is likely to impact the overall quality of the terminally ill patient's end-of-life care, by disrupting their continuity of care. Regardless of one's office location, the consulting provider must perform an independent assessment; evaluating a terminally ill individual's request for medical aid in dying, eligibility and capacity to make an informed decision. This requirement is already part of the standard of care, reaffirmed by the process outlined in HB 5898. Furthermore, any provider who does not meet this standard would not be afforded the protections that HB 5898 provides.

Compassion & Choices recommends removing all three of these provisions in the bill. Medical aid in dying is the most heavily regulated end-of-life care option — far more regulated than all other end-of-life care options — which have far greater risk for abuse or coercion, such as palliative sedation. Palliative sedation requires another person (e.g., a doctor) to administer medication to put the person into a coma and to withhold fluids and nutrition until the patient dies from dehydration or the underlying disease. Yet, there is absolutely no regulatory oversight of palliative sedation. Doctors are trusted to practice medicine, rather than being subjected to unnecessary government red tape and intrusion. Requiring multiple requests, especially in a particular format as required by HB 05217, unfairly stigmatizes and discriminates against terminally ill patients who decide they prefer medical aid in dying over other end-of-life care options. No other end-of-life care

option (including removal from a ventilator, palliative sedation or VSED) requires multiple requests.

# Replace use of the incorrect term "competency" with "capacity"

The current legislation confuses the terms "competency" and "capacity." Competency is a legal term referring to individuals "having sufficient ability... possessing the requisite natural or legal qualifications" to engage in a given endeavor. It is a legal term that will have little meaning to doctors because they do not determine competency; only judges can do that and they have no role in determining eligibility for medical aid in dying. The term "capacity" refers to an assessment of the individual's psychological abilities to form rational decisions, specifically the individual's ability to understand, appreciate, and manipulate information and form rational decisions. The term "capacity" is the one that doctors and other healthcare providers use in medicine, and the more appropriate terminology for this legislation.

# Use of the term "qualified patient"

The terms "patient" and "qualified patient" are used interchangeably throughout the legislation. A patient is only considered "qualified" after they have satisfied the requirements of the Act in order to obtain a prescription for aid-in-dying medication. As such, Compassion & Choices suggests several instances where "qualified" be removed from the language describing the patient.

# **Common Misconceptions about Medical Aid in Dying**

Below is some clarifying information about common misperceptions about medical aid in dying.

# Medical Aid in Dying is NOT the Same as Euthanasia

Medical aid in dying is fundamentally different from euthanasia. As noted earlier, medical aid in dying is authorized in seven states, as well as the District of Columbia. With medical aid in dying, the terminally ill person remains in charge of the process from beginning to end and must take the medication themselves. As a result, patients always maintain the decision-making authority to change their mind. Euthanasia is commonly given as a lethal injection by another person. Euthanasia is illegal throughout the United States. Compassion & Choices does not support euthanasia because someone else – not the dying person – decides and acts to cause death.

# Medical Aid in Dying is NOT Suicide

There is a fundamental difference between the practice of medical aid in dying and suicide. With medical aid in dying the person is already going to die -- the only question is how they are going to die. With suicide, a person is prematurely ending one's life, often by violent means. Suicide is often the tragic result of an unrecognized or untreated reversible mental health disorder, such as depression or addiction. It is traumatic for the person's family and community. In contrast, the data about medical aid in dying demonstrates that it brings

families together, with a sense of completeness and love, during an extraordinarily difficult time.

Major national organizations with an expertise in the field have recognized the distinction between medical aid in dying and suicide:

- The American Association of Suicidology, a nationally recognized organization comprised of respected researchers and mental health professionals, that promotes prevention of suicide through research, public awareness programs, education and training, asserts medical aid in dying is fundamentally distinct from suicide and that the term "physician-assisted suicide" should not be used.<sup>51</sup>
- The American College of Legal Medicine filed an amicus brief before the United States Supreme Court in 1996 rejecting the term suicide to describe medical aid in dying. The organization also adopted a resolution in 2008 in which they "publicly advocated the elimination of the word 'suicide' when referencing this end-of-life care option." 52
- According to the American Psychological Association, medical aid in dying and suicide have "profound psychological differences."

The medical aid-in-dying laws in Oregon,<sup>54</sup> Washington,<sup>55</sup> Vermont,<sup>56</sup> California,<sup>57</sup> Colorado,<sup>58</sup> the District of Columbia<sup>59</sup> and Hawai'i<sup>60</sup> emphasize that: "Actions taken in

<sup>&</sup>lt;sup>51</sup>Statement of the American Association of Suicidology: "Suicide" is not the same as "Physician aid in dying" Approved October 30, 2017. Available from:

http://www.suicidology.org/portals/14/docs/press%20release/aas%20pad%20statement%20approved%20 10.30.17%20ed%2010-30-17.pdf

<sup>&</sup>lt;sup>52</sup> ACLM [American College of Legal Medicine] POLICY ON AID IN DYING. Available from: https://c.ymcdn.com/sites/www.aclm.org/resource/collection/11DA4CFF-C8BC-4334-90B0-2ABBE5748D 08/Policy\_On\_Aid\_In\_Dying.pdf

<sup>&</sup>lt;sup>53</sup> American Psychological Association. 2017. Resolution on Assisted Dying. Retrieved from: http://www.apa.org/about/policy/assisted-dying-resolution.aspx.

<sup>&</sup>lt;sup>54</sup> Oregon Death With Dignity Act. Oregon Revised Statute. Chapter 127. Enacted October 27, 1997. Available from

 $<sup>\</sup>underline{http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ors.aspx.}$ 

<sup>&</sup>lt;sup>55</sup> Washington Death With Dignity Act. Complete Chapter 70.245 RCW, Complete Chapter. Enacted November 4, 2008. Available from http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245.

<sup>&</sup>lt;sup>56</sup> Montana Supreme Court Ruling Baxter v. Montana. December 2009 Available from <a href="https://www.compassionandchoices.org/wp-content/uploads/2017/01/Montana-Supreme-Court-Opinion.pgdf">https://www.compassionandchoices.org/wp-content/uploads/2017/01/Montana-Supreme-Court-Opinion.pgdf</a>

 <sup>&</sup>lt;sup>57</sup> California End of Life Option Act. SB-128 End of Life. Enacted October 2015. Available from http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=201520160SB128&search\_keywords=
 <sup>58</sup> Colorado End of Life Options Act, Proposition 106, Passed November 8, 2016, Pending implementation. Retrieved from:

http://coendoflifeoptions.org./wp-content/uploads/2016/06/Full-Text-of-Measure.pdf

accordance with [the Act] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law." These laws make this distinction because a person who is prematurely ending their life versus a person opting for medical aid in dying who has a terminal diagnosis and a prognosis of six months or less to live. The terminally ill person is not deciding to die; the disease already is taking their life. The terminally ill person who opts for medical aid in dying is simply deciding not to prolong a difficult and painful dying process. <sup>61</sup>

# Medical Aid-in-Dying Laws Do Not Increase Suicide Rates

There is absolutely no evidence that medical aid in dying impacts suicide rates. In fact, if you compare the suicide ranking of states between 2005 and 2017, you will note that nearly every state that passed laws authorizing medical aid in dying dropped in the rankings after they passed them.<sup>62</sup> Western states have higher suicide rates than the national average because they have higher gun ownership rates (guns are used to commit more than half of all suicides nationwide). Experience also demonstrates that authorizing medical aid in dying actually prevents suicides among the terminally ill because when empowered at the end of life, and offered a gentle option, people aren't forced to take their lives by violent means, afraid and alone, to end their suffering.

# Additional Frequently Raised Questions Can't People Just Kill Themselves Using Other Means?

Good Public Policy Does Not Abandon People at the End of Life. By failing to enact legislation authorizing medical aid in dying, we are forcing dying patients to act in secrecy, spending their final moments alone or putting their loved ones at legal risk by implicating them in a crime. Nobody should have to die alone, and no family member should have to endure finding a loved one who resorted to ending their life in isolation, when another,

<sup>&</sup>lt;sup>59</sup> District of Columbia, Death with Dignity Act, Available from: <a href="https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page\_content/attachments/Death%20With%20Dignity%20Act.FINAL.pdf">https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page\_content/attachments/Death%20With%20Dignity%20Act.FINAL.pdf</a>

<sup>&</sup>lt;sup>60</sup> Hawaii Our Care, Our Choice Act, HB 2739, Signed April 4, 2018. Pending Enactment. Available from: https://www.capitol.hawaii.gov/session2018/bills/HB2739 HD1 .pdf

<sup>&</sup>lt;sup>61</sup> Reisch, T., et al. (1999) Efficacy of Crisis

<sup>&</sup>lt;sup>62</sup> National Center for Health Statistics, Suicide Mortality by State. Available from: <a href="https://www.cdc.gov/nchs/pressroom/sosmap/suicide-mortality/suicide.htm">https://www.cdc.gov/nchs/pressroom/sosmap/suicide-mortality/suicide.htm</a>

<sup>&</sup>lt;sup>63</sup> Anglemyer, A., Horvath, T., & Rutherford, G. (2014). The accessibility of firearms and risk for suicide and homicide victimization among household members: A systematic review and meta-analysis. Annals of Internal Medicine, 160(2), 101–110.

<sup>&</sup>lt;sup>64</sup> Miller, M., & Hemenway, D. (2008). Guns and suicide in the United States. New England Journal of Medicine, 359(10), 989–991.

<sup>&</sup>lt;sup>65</sup> Brent, D. A., & Bridge, J. (2003). Firearms availability and suicide: Evidence, interventions, and future directions. The American Behavioral Scientist, 46(9), 1192–1210

more humane option is possible. Authorizing medical aid in dying replaces covert action with a transparent, regulated medical practice that ensures safety.

# Isn't Medical Aid in Dying In Conflict with Religion?

Every religion has its own values, tenets and rituals around death. A person's individual beliefs are an important factor in their understanding of dying and their approach to it. While some faiths counsel their followers that advancing the time of death to avoid suffering is immoral, others just as strongly counsel the dying and their families to leave this life in the manner most meaningful to them. Deciding to use medical aid in dying is only one end-of-life care option. People who are strongly opposed to this end-of-life care option need not use it or participate in it. For people who face unbearable suffering, this option can give them both courage and hope, allowing them to live fully as long as possible and to die peacefully when death is imminent. It is a personal decision that only the individual can make, in consultation with their doctor, loved ones and faith or spiritual leaders.

#### Conclusion

Decisions about death belong to the dying, and good policy enables them to engage in open conversations with their doctors, their loved ones, and their faith or spiritual leaders about their physical and spiritual needs at the end of life. Without this law, doctors and family members risk prosecution if they attempt to fully discuss and offer all medical options at the end of life.

The bill before you is responsible legislation that responds to your many constituents who believe that medical aid in dying should be available as an end-of-life care option. Allowing this legislation to become law is the right thing for Connecticut because it will bring peace of mind to state residents at -- or near the end -- of their lives. I urge you to review the evidence, experience, data and strong public support for this end-of-life care option to guide your policymaking.

Thank you again, Chair Steinberg, Chairwoman Abrams and Members of the Committee, for your timely leadership on this important issue.

Kim Callinan Chief Executive Officer, Compassion & Choices kcallinan@compassionandchoices.org www.compassionandchoices.org

# **Compassion & Choices Policy Review & Suggested Amendments**

Newly proposed language is <u>underlined</u>, language suggested for removal is <del>struck through.</del>

General Assembly

January Session, 2019

Committee Bill 5898 *LCO No. 3838* 

Referred to Committee on PUBLIC HEALTH

Introduced by: (PH)

### AN ACT CONCERNING AID IN DYING FOR TERMINALLY ILL PATIENTS

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (NEW) (Effective October 1, 2019) As used in this section and sections 2 to 19, inclusive, of this act:

- (1) "Adult" means a person who is eighteen years of age or older;
- (2) "Aid in dying" means the medical practice of a physician prescribing medication to a qualified patient who is terminally ill, which medication a qualified patient may self-administer to bring about his or her death;
- (3) "Attending physician" means the physician who has primary responsibility for the medical care of a patient and treatment of a patient's terminal illness;
- (4) "Competent Capable or mental capacity" means, in the opinion of a patient's attending physician, consulting physician, or psychiatrist, psychologist or a court, that a patient has the capacity ability to understand and acknowledge the nature and consequences of health care decisions, including the benefits and disadvantages of treatment, to make an informed decision and to communicate such decision to a health care provider, including communicating through a person familiar with a patient's manner of communicating;
- (5) "Consulting physician" means a physician other than a patient's attending physician who (A) is qualified by specialty or experience to make a professional diagnosis and prognosis regarding a patient's terminal illness; and (B) does not routinely share office space with a patient's attending physician;

- (6) "Counseling" means one or more consultations as necessary between a psychiatrist or a psychologist and a patient for the purpose of determining that a patient is competent capable and not suffering from depression or any other psychiatric or psychological disorder that causes impaired judgment;
- (7) "Health care provider" means a person licensed, certified or otherwise authorized or permitted by the laws of this state to administer health care or dispense medication in the ordinary course of business or practice of a profession, including, but not limited to, physician, psychiatrist, psychologist or pharmacist;
- (8) "Health care facility" means a hospital, residential care home, nursing home or rest home, as such terms are defined in section 19a-490 of the general statutes;
- (9) "Informed decision" means a decision by a qualified terminally ill patient to request and obtain a prescription for medication that the qualified patient may self-administer for aid in dying, that is based on an understanding and acknowledgment of the relevant facts and after being fully informed by the attending physician of: (A) The qualified terminally ill patient's medical diagnosis and prognosis; (B) the potential risks associated with self-administering the medication to be prescribed; (C) the probable result of taking the medication to be dispensed or prescribed; and (D) the feasible alternatives to aid in dying and healthcare treatment options, including, but not limited to, hospice and palliative care;
- (10) "Medically confirmed" means the medical opinion of the attending physician has been confirmed by a consulting physician who has examined the patient and the patient's relevant medical records;
- (11) "Palliative care" means health care centered on a seriously ill patient and such patient's family that (A) optimizes a patient's quality of life by anticipating, preventing and treating a patient's suffering throughout the continuum of a patient's terminal illness, (B) addresses the physical, emotional, social and spiritual needs of a patient, (C) facilitates patient autonomy, patient access to information and patient choice, and (D) includes, but is not limited to, discussions between a patient and a health care provider concerning a patient's goals for treatment and appropriate treatment options available to a patient, including hospice care and comprehensive pain and symptom management;
- (12) "Patient" means a person who is under the care of a physician;

- (13) "Pharmacist" means a person licensed to practice pharmacy pursuant to chapter 400j of the general statutes;
- (14) "Physician" means a person licensed to practice medicine and surgery pursuant to chapter 370 of the general statutes;
- (15) "Psychiatrist" means a physician specializing in psychiatry and licensed pursuant to chapter 370 of the general statutes;
- (16) "Psychologist" means a person licensed to practice psychology pursuant to chapter 383 of the general statutes;
- (17) "Qualified patient" means a <u>competent capable</u> adult who is a resident of this state, has a terminal illness and has satisfied the requirements of this section and sections 2 to 9, inclusive, of this act, in order to obtain aid in dying;
- (18) "Self-administer" means a qualified patient's <u>voluntary</u>, <u>conscious and affirmative</u> act of <u>ingesting</u> taking-medication into his or her own body; and
- (19) "Terminal illness" means the final stage of an incurable and irreversible medical condition that an attending physician anticipates, within reasonable medical judgment, will produce a patient's death within six months.
- Sec. 2. (NEW) (Effective October 1, 2019) (a) A patient who (1) is an adult, (2) is competent capable, (3) is a resident of this state, (4) has been determined by such patient's attending physician to have a terminal illness, and (5) has voluntarily expressed his or her wish to receive aid in dying, may request aid in dying by making two written oral requests and one written request to such patient's attending physician pursuant to sections 3 and 4 of this act.
- (b) No person, including, but not limited to, an agent under a living will, an attorney-in-fact under a durable power of attorney, a guardian, or a conservator, may act on behalf of a patient for purposes of this section, section 1 or sections 3 to 19 inclusive of this act.
- Sec. 3. (NEW) (Effective October 1, 2019) (a) A patient wishing to receive aid in dying shall submit two <a href="written\_oral">written\_oral</a> requests to such patient's attending physician. <a href="in substantially the form set forth in section 4 of this act.">in substantially the form set forth in section 4 of this act.</a> A patient's second <a href="written\_oral">written\_oral</a> request for aid in dying shall be submitted not earlier than fifteen days after the date on which a patient submits the first <a href="oral">oral</a> request. A valid written request for aid in dying under sections 1 and 2 of this act shall be substantially the form set forth in section 4 of this act and <a href="sections-4-to-sections-4">sections-4 to-sections-4</a> to

19, inclusive, of this act shall be signed and dated by the patient. Each The written request shall be witnessed by at least two persons in the presence of the patient. Each person serving as a witness shall attest, in writing, that to the best of his or her knowledge and belief: (1) the patient appears to be of sound mind and (2) the patient is acting voluntarily and not being coerced to sign the request., and (3) At least one of the the witnesses is not: (A) A relative of the patient by blood, marriage or adoption, (B) entitled to any portion of the estate of the patient upon the patient's death, under any will or by operation of law, or (C) an owner, operator or employee of a health care facility where the patient is a resident or receiving medical treatment.

- (b) No At least one of the persons serving as a witness to a patient's request to receive aid in dying shall not be: (1) A relative of such patient by blood, marriage or adoption; (2) at the time the request is signed, entitled to any portion of the estate of the patient upon the patient's death, under any will or by operation of law; (3) an owner, operator or employee of a health care facility where the patient is a resident or receiving medical treatment; or (4) such patient's attending physician at the time the request is signed.
- (c) Any patient's act of requesting aid in dying or a qualified patient's self-administration of medication prescribed for aid in dying shall not provide the sole basis for appointment of a conservator or guardian for such patient or qualified patient.

Sec. 4. (NEW) (Effective October 1, 2019) A request for aid in dying as authorized by this section, sections 1 to 3, inclusive, of this act and sections 5 to 19, inclusive, of this act shall be in substantially the following form:

### REQUEST FOR MEDICATION TO AID IN DYING 124

I, ...., am an adult of sound mind.

I am a resident of the State of Connecticut.

I am suffering from ...., which my attending physician has determined is an incurable and irreversible medical condition that will, within reasonable medical judgment, result in death within six months from the date on which this document is executed. This diagnosis of a terminal illness has been medically confirmed by another physician.

I have been fully informed of my diagnosis, prognosis, the nature of medication to be dispensed or prescribed to aid me in dying, the potential associated risks, the expected result, feasible alternatives to aid in dying and additional health care treatment options, including palliative care and the availability of counseling with a psychologist, psychiatrist or licensed clinical social worker.

I request that my attending physician dispense or prescribe medication that I may self-administer for aid in dying. I authorize my attending physician to contact a pharmacist to fill the prescription for such medication, upon my request.

#### **INITIAL ONE:**

- .... I have informed my family of my decision and taken family opinions into consideration.
- .... I have decided not to inform my family of my decision.
- .... I have no family to inform of my decision.

I understand that I have the right to rescind this request at any time.

I understand the full import of this request and I expect to die if and when I take the medication to be dispensed or prescribed. I further understand that although most deaths occur within three hours, my death may take longer and my attending physician has counseled me about this possibility.

I accept full responsibility for my decision to request aid in dying. Signed: ....

Dated: ....

### **DECLARATION OF WITNESSES**

By initialing and signing below on the date the person named above signs, I declare that: Witness 1 .... Witness 2 ....

### Initials .... Initials ....

- .... 1. The person making and signing the request is personally known to me or has provided proof of identity;
- .... 2. The person making and signing the request signed this request in my presence on the date of the person's signature;
- .... 3. The person making the request appears to be of sound mind and not under duress, fraud or undue influence;
- .... 4. I am not the attending physician for the person making the request;
- .... 5. The person making the request is not my relative by blood, marriage or adoption;
- .... 6. I am not entitled to any portion of the estate of the person making the request upon such person's death under any will or by operation of law; and
- .... 7. I am not an owner, operator or employee of a health care facility where the person making the request is a resident or receiving medical treatment. NOTE: One witness shall not be a relative (by blood, marriage or adoption) of the person signing this request, shall not be entitled to any portion of the person's estate upon death and shall not own, operate or be employed at a health care facility where the person is a patient or resident.

Printed Name of Witness 1 .... Date ....

Signature of Witness 1 .... Date ....

Printed Name of Witness 2 ....

Signature of Witness 2 .... Date ....

Sec. 5. (NEW) (Effective October 1, 2019) (a) A qualified terminally ill patient may rescind his or her request for aid in dying at any time and in any manner without regard to his or her mental state.

- (b) An attending physician shall offer a qualified terminally ill patient an opportunity to rescind his or her request for aid in dying at the time such patient submits a second written request for aid in dying to the 187 attending physician.
- (c) No attending physician shall dispense or prescribe medication for aid in dying without the attending physician first offering the qualified terminally ill patient a second opportunity to rescind his or her request for aid in dying.

Sec. 6. (NEW) (Effective October 1, 2019) When an attending physician is presented with a patient's first written request for aid in dying made pursuant to sections 2 to 4, inclusive, of this act, the attending physician shall:

- (1) Make a determination that the patient (A) is an adult, (B) has a terminal illness, (C) is competent capable, and (D) has voluntarily requested aid in dying. Such determination shall not be made solely on the basis of age, disability or any specific illness;
- (2) Require the patient to demonstrate residency in this state by presenting: (A) A Connecticut driver's license <u>or identification card</u>; (B) a valid voter registration record authorizing the patient to vote in this state; or (C) any other government-issued document that the attending physician reasonably believes demonstrates that the patient is a current resident of this state;
- (3) Ensure that the patient is making an informed decision by informing the patient of: (A) The patient's medical diagnosis; (B) the patient's prognosis; (C) the potential risks associated with self-administering the medication to be dispensed or prescribed for aid in dying; (D) the probable result of self-administering the medication to be dispensed or prescribed for aid in dying; (E) the feasible alternatives to aid in dying and health care

treatment options including, but not limited to, <u>hospice and</u> palliative care; and (F) the availability of counseling with a psychologist, psychiatrist or licensed clinical social worker; and

- (4) Refer the patient to a consulting physician for medical confirmation of the attending physician's diagnosis of the patient's terminal illness, the patient's prognosis and for a determination that the patient is competent capable and acting voluntarily in requesting aid in dying.
- Sec. 7. (NEW) (Effective October 1, 2019) In order for a patient to be found to be a qualified patient for the purposes of this section, sections 1 to 6, inclusive, of this act and sections 8 to 19, inclusive, of this act, a consulting physician shall: (1) Examine the patient and the patient's relevant medical records; (2) confirm, in writing, the attending physician's diagnosis that the patient has a terminal illness; (3) verify that the patient is competent capable, is acting voluntarily and has made an informed decision to request aid in dying; and (4) refer the patient for counseling, if required in accordance with section 8 of this act.
- Sec. 8. (NEW) (Effective October 1, 2019) (a) If, in the medical opinion of the attending physician or the consulting physician, a patient may be suffering from a psychiatric or psychological condition including, but not limited to, depression, that is causing impaired judgment, either the attending or consulting physician shall refer the patient for counseling to determine whether the patient is competent capable to request aid in dying.
- (b) An attending physician shall not provide the patient aid in dying until the person providing such counseling determines that the patient is not suffering a psychiatric or psychological condition including, but not limited to, depression, that is causing impaired judgment.
- Sec. 9. (NEW) (Effective October 1, 2019) (a) After an attending physician and a consulting physician determine that a patient is an eligible qualified-patient, in accordance with sections 6 to 8, inclusive, of this act and after such qualified patient submits a second <u>oral</u> request for aid in dying in accordance with sections 3 and 4 of this act, the attending physician shall:
- (1) Recommend to the qualified terminally ill patient that he or she notify his or her next of kin of the qualified terminally ill patient's request for aid in dying and inform the qualified terminally ill patient that a failure to do so shall not be a basis for the denial of such request;

- (2) Counsel the qualified terminally ill patient concerning the importance of: (A) Having another person present when the qualified patient self-administers the medication dispensed or prescribed for aid in dying; and (B) not taking the medication in a public place;
- (3) Inform the qualified terminally ill patient that he or she may rescind his or her request for aid in dying at any time and in any manner;
- (4) Verify, immediately before dispensing or prescribing medication for aid in dying, that the qualified terminally ill patient is making an informed decision;
- (5) Fulfill the medical record documentation requirements set forth in section 10 of this act; and
- (6) (A) Dispense such medication, including ancillary medication intended to facilitate the desired effect to minimize the qualified patient's discomfort, if the attending physician is authorized to dispense such medication, to the qualified patient; or (B) upon the qualified patient's request and with the qualified patient's written consent (i) contact a pharmacist and inform the pharmacist of the prescription, and (ii) personally deliver the written prescription, by mail, facsimile or electronic transmission to the pharmacist, who shall dispense such medication directly to the qualified patient, the attending physician or an expressly identified agent of the qualified patient.
- (b) The person signing the qualified patient's death certificate shall list the underlying terminal illness as the cause of death.
- Sec. 10. (NEW) (Effective October 1, 2019) The attending physician shall ensure that the following items are documented or filed in a qualified patient's medical record:
- (1) The basis for determining that a qualified patient is an adult and a resident of the state;
- (2) All oral requests by a qualified patient for medication for aid in dying;
- (3) All written requests by a qualified patient for medication for aid in dying;
- (4) The attending physician's diagnosis of a qualified patient's terminal illness and prognosis, and a determination that a qualified patient is competent capable, is acting voluntarily and has made an informed decision to request aid in dying;

- (5) The consulting physician's confirmation of a qualified patient's diagnosis and prognosis, confirmation that a qualified patient is competent capable, is acting voluntarily and has made an informed decision to request aid in dying;
- (6) A report of the outcome and determinations made during counseling, if counseling was recommended and provided in accordance with section 8 of this act;
- (7) Documentation of the attending physician's offer to a qualified patient to rescind his or her request for aid in dying at the time the attending physician dispenses or prescribes medication for aid in dying; and
- (8) A statement by the attending physician indicating that (A) all requirements under this section and sections 1 to 9, inclusive, of this act have been met, and (B) the steps taken to carry out a qualified patient's request for aid in dying, including the medication dispensed or prescribed.
- Sec. 11. (NEW) (Effective October 1, 2019) Any person, other than a qualified patient, in possession of medication dispensed or prescribed for aid in dying that has not been self-administered shall return such medication to the attending physician or the Commissioner of Consumer Protection in accordance with section 21a-252 of the general statutes.
- Sec. 12. (NEW) (Effective October 1, 2019) (a) Any provision of a contract, including, but not limited to, a contract related to an insurance policy or annuity, conditioned on or affected by the making or rescinding of a request for aid in dying shall not be valid.
- (b) On and after October 1, 2019, the sale, procurement or issuance of any life, health or accident insurance or annuity policy or the rate charged for any such policy shall not be conditioned upon or affected by the making or rescinding of a request for aid in dying.
- (c) A qualified patient's act of requesting aid in dying or self- administering medication dispensed or prescribed for aid in dying shall not constitute suicide for any purpose, including, but not limited to, a criminal prosecution under section 53a-56 of the general statutes.
- Sec. 13. (NEW) (Effective October 1, 2019) (a) As used in this section, "participate in the provision of medication" means to perform the duties of an attending physician or consulting physician, a psychiatrist, psychologist or pharmacist in accordance with the provisions of sections 2 to 10, inclusive, of this act. "Participate in the provision of

- medication" does not include: (1) Making an initial diagnosis of a patient's terminal illness; (2) informing a patient of his or her medical diagnosis or prognosis; (3) informing a patient concerning the provisions of this section, sections 1 to 12, inclusive, of this act and sections 16 to 19, inclusive, of this act, upon the patient's request; or (4) referring a patient to another health care provider for aid in dying.
- (b) Participation in any act described in sections 1 to 12, inclusive, of this act and sections 16 to 19, inclusive, of this act by a patient, health care provider or any other person shall be voluntary. Each health care provider shall individually and affirmatively determine whether to participate in the provision of medication to a qualified patient for aid in dying. A health care facility shall not require a health care provider to participate in the provision of medication to a qualified patient for aid in dying, but may prohibit such participation in accordance with subsection (d) of this section.
- (c) If a health care provider or health care facility chooses not to participate in the provision of medication to a qualified patient for aid in dying, upon request of a qualified terminally ill patient, such health care provider or health care facility shall transfer all relevant medical records to any health care provider or health care facility, as directed by a qualified terminally ill patient.
- (d) A health care facility may adopt written policies prohibiting a health care provider associated with such health care facility from participating in the provision of medication to a patient for aid in dying, provided such facility provides written notice of such policy and any sanctions for violation of such policy to such health care provider.

  Notwithstanding the provisions of this subsection or any policies adopted in accordance with this subsection, a health care provider may: (1) Diagnose a patient with a terminal illness; (2) inform a patient of his or her medical prognosis; (3) provide a patient with information concerning the provisions of this section, sections 1 to 12, inclusive, of this act and sections 16 to 19, inclusive, of this act, upon a 358 patient's request; (4) refer a patient to another health care facility or health care provider; (5) transfer a patient's medical records to a health care provider or health care facility, as requested by a patient; or (6) participate in the provision of medication for aid in dying when such health care facility that prohibits participation in the provision of such medication.
- (e) Except as provided in a policy adopted in accordance with subsection (d) of this section, no health care facility may subject an employee or other person who provides services under contract with the health care facility to disciplinary action, loss of privileges, loss of membership or any other penalty for participating, or refusing to participate, in the

provision of medication or related activities in good faith compliance with the provisions of this section, sections 1 to 12, inclusive, of this act and sections 16 to 19, inclusive, of this act.

- Sec. 14. (NEW) (Effective October 1, 2019) (a) A person is guilty of murder when such person, without authorization of a patient, wilfully alters or forges a request for aid in dying, as described in sections 3 and 4 of this act, or conceals or destroys a rescission of such a request for aid in dying with the intent or effect of causing the patient's death.
- (b) A person is guilty of murder when such person coerces or exerts undue influence on a patient to complete a request for aid in dying, as described in sections 3 and 4 of this act, or coerces or exerts undue influence on a patient to destroy a rescission of such request with the intent or effect of causing the patient's death.
- Sec. 15. (NEW) (Effective October 1, 2019) (a) Nothing in sections 1 to 14, inclusive, of this act or sections 16 to 19, inclusive, of this act authorizes a physician or any other person to end another person's life by lethal injection, mercy killing, assisting a suicide or any other active euthanasia.
- (b) No action taken in accordance with sections 1 to 14, inclusive, of this act or sections 16 to 19, inclusive, of this act shall constitute causing or assisting another person to commit suicide in violation of section 53a-54a or 53a-56 of the general statutes.
- (c) No person shall be subject to civil or criminal liability or professional disciplinary action, including, but not limited to, revocation of such person's professional license, for (1) participating in the provision of medication or related activities in good faith compliance with the provisions of sections 1 to 14, inclusive, of this act and sections 16 to 19, inclusive, of this act, or (2) being present at the time a qualified patient self-administers medication dispensed or prescribed for aid in dying.
- (d) An attending physician's dispensing of, or issuance of a prescription for medication for aid in dying or a patient's request for aid in dying, in good faith compliance with the provisions of sections 1 to 19, inclusive, of this act shall not constitute neglect for the purpose of any law or provide the sole basis for appointment of a guardian or conservator for such patient.

Sec. 16. (NEW) (Effective October 1, 2019) Sections 1 to 15, inclusive, of this act or sections 17 to 19, inclusive, of this act do not limit liability for civil damages resulting from negligent conduct or intentional misconduct by any person.

Sec. 17. (NEW) (Effective October 1, 2019) (a) Any person who knowingly possesses, sells or delivers medication dispensed or prescribed for aid in dying for any purpose other than delivering such medication to a qualified patient, or returning such medication in accordance with section 11 of this act, shall be guilty of a class D felony.

(b) Nothing in sections 1 to 16, inclusive, of this act or section 18 or 19 of this act shall preclude criminal prosecution under any provision of law for conduct that is inconsistent with said sections.

Sec. 18. (NEW) (Effective October 1, 2019) Nothing in sections 1 to 17, inclusive, of this act or section 19 of this act shall limit the jurisdiction or authority of the nonprofit entity designated by the Governor to serve as the Connecticut protection and advocacy system under chapter 813 of the general statutes.

Sec. 19. (NEW) (Effective October 1, 2019) No person who serves as an attending physician, consulting physician or a witness as described in section 3 of this act, or otherwise participates in the provision of medication for aid in dying to a qualified patient, shall inherit or receive any part of the estate of such qualified patient, whether under the provisions of law relating to intestate succession or as a devisee or legatee, or otherwise under the will of such qualified patient, or receive any property as beneficiary or survivor of such qualified patient after such qualified patient has self-administered medication dispensed or prescribed for aid in dying.

This act shall take effect as follows and shall amend the following sections:		
Section 1	October 1, 2019	New section
Sec. 2	October 1, 2019	New section
Sec. 3	October 1, 2019	New section
Sec. 4	October 1, 2019	New section
Sec. 5	October 1, 2019	New section
Sec. 6	October 1, 2019	New section
Sec. 7	October 1, 2019	New section
Sec. 8	October 1, 2019	New section

Sec. 9	October 1, 2019	New section
Sec. 10	October 1, 2019	New section
Sec. 11	October 1, 2019	New section
Sec. 12	October 1, 2019	New section
Sec. 13	October 1, 2019	New section
Sec. 14	October 1, 2019	New section
Sec. 15	October 1, 2019	New section
Sec. 16	October 1, 2019	New section
Sec. 17	October 1, 2019	New section
Sec. 18	October 1, 2019	New section
Sec. 19	October 1, 2019	New section

# Statement of Purpose:

To provide aid in dying to terminally ill patients.

[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]

# Co-Sponsors:

REP. STEINBERG, 136th Dist.; REP. GRESKO, 121st Dist.

H.B. 5898